

Feasibility and Concurrent Validity of Cerebral Palsy Quality of Life for Children (CP QOL-Child) in Thai Version

Saipin Prasertsukdee PhD¹, Nisasri Sermpol MS¹, Kwanchanok Suwanna MS¹, Wimonrat Jarumethitanont MS¹, Sivaporn Limpanilchart MS¹, Piyatida Khajornchaikul PhD², Oranee Sanmaneechai MD³

¹ Faculty of Physical Therapy, Mahidol University, Salaya, Nakhon Prathom, Thailand

² Faculty of Public Health, Mahidol University, Bangkok, Thailand

³ Faculty of Medicine, Siriraj Hospital, Mahidol University, Bangkok, Thailand

Background: The Cerebral Palsy Quality of Life for Children (CP QOL-Child) questionnaires are condition-specific QOL measures for children with CP focusing on perspectives of children with CP on their quality of life, not on their physical difficulties. The perspectives of well-being are core concepts of quality of life. The CP QOL-Child has already been translated in Thai and the reliability is excellent. The validity after the translation has not been conducted and is required. therefore, it is needed to examine the validity to ensure the clinical practicality.

Objective: To examine feasibility and concurrent validity of the CP QOL-Child (Thai version).

Materials and Methods: Eighty-five primary caregivers of 4- to 12-year-old children and 65 children between 9- and 12-years-old, who passed the inclusion criteria, completed three questionnaires including the CP QOL-Child (Thai version), the PedsQL 4.0 Generic Core Scales, and the PedsQL 3.0 CP module (Thai version).

Results: For feasibility of the CP QOL-Child, no missing items were found in any items for the child self-report. For parent proxy report, missing items were scattered and from 1.2% to 7.1%. For concurrent validity, according to the total scores of both versions, the self-report and the parent proxy, the correlation coefficients between CP QOL-Child and PedsQL 4.0 Generic Core Scales were 0.23 to 0.25 meaning no or little correlations, at significance level of 0.05. The correlation coefficients between the CP QOL-Child and the PedsQL CP module were 0.38 to 0.49, meaning fair correlations, at significance level of 0.01.

Conclusion: The feasibility of the CP QOL-Child (Thai version) was reportedly acceptable. The concurrent validity support that the CP QOL-Child may not measure the quality of life at the same constructs as the PedsQL. The CP QOL-Child asks the client's perspectives of quality of life (QOL) while both PedsQL modules ask the client's difficulties that might relate to QOL.

Keywords: Health-related quality of life, CP QOL-Child, Cerebral palsy, Feasibility, Validity

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Many previous studies showed that the quality of life in children with cerebral palsy (CP) was less than for typical children⁽¹⁻⁸⁾. However, some studies^(9,10) showed that the children with CP reportedly had similar quality of life as in typical children. The similar results were found in the studies of the quality of life in children with CP in Thailand⁽¹¹⁻¹³⁾. Viehweger et al in 2008⁽¹⁴⁾ reported many QOL measures were

developed for the general children, or for non-specific chronic disease but used in children with CP. Only a few QOL measures were specifically developed for children with CP. In Thailand, one generic and two CP-specific health-related quality of life (HRQOL) instruments were translated to Thai⁽¹⁵⁻¹⁷⁾ including the Pediatric Quality of Life Inventory 4.0 Generic Core Scales (PedsQL 4.0), the Pediatric Quality of Life Inventory 3.0 Cerebral Palsy Module (PedsQL 3.0 CP), and the Cerebral Palsy Quality of Life Questionnaire for children (CP QOL-Child). Both modules of the PedsQL measures were reported acceptable, reliable, and valid psychometrics properties^(15,16). The CP QOL-Child is specifically designed to measure quality of life based on the perspectives of parents and children with CP⁽¹⁸⁻²⁰⁾. The questionnaires reportedly had acceptable internal consistencies and test-retest reliabilities⁽²⁰⁾. Additionally, the CP QOL-Child questionnaires were moderately correlated with other quality of life,

Correspondence to:

Prasertsukdee S.

Faculty of Physical Therapy, Mahidol University, 999 Phutthamonthon Sai 4 Road, Salaya, Phutthamonthon, Nakhon Pathom 73170, Thailand.

Phone: +66-2-4415450, Fax: +66-2-4415454

Email: saipin.pra@mahidol.edu

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health, and functioning measures⁽²⁰⁾. Prasertsukdee et al translated the CP QOL-Child to Thai based on the test developers' translation guidelines⁽²¹⁾. They found excellent internal consistency and test-retest reliabilities⁽¹⁷⁾. The aims of the present study were to examine feasibility and concurrent validity of CP QOL-Child in Thai version as the original developers' translation guidelines.

Materials and Methods

The participants in the present study consisted of two groups including children with CP and primary caregivers who took care of children with CP. Sixty-five children with CP aged 9 to 12 years that attended in special schools, rehabilitation centers, or physical therapy clinics in Bangkok and perimeter were included in this study. Inclusion criteria for the children were that they studied at least in grade 1 and was able to read or understand simple sentences. Their language understanding was screened and rated by repeating five questions randomly selected from the CP QOL-Child questionnaire. They passed if they rated the same choices at least three of five items. The second group was eighty-five parents or primary caregivers of children with CP age between 4 and 12 years. Inclusion criteria for the caregivers were they were most responsible for day-to-day caring of the child, currently lived with the child for at least six months, and they could read or understand Thai.

CP QOL-Child are questionnaires for children with CP age 4 to 12 years, containing a parent proxy version for parents who have children with CP age 4 to 12 years old (66 items) and self-report version for children with CP age 9 to 12 years (53 items). The questionnaires ask the perspectives of quality of life including 1) health and social acceptance, 2) health and participation, 3) activities participation, 4) emotional and self-acceptance, 5) pain and capability, 6) access to service, and 7) family health.

PedsQL 4.0 Generic Core Scale and PedsQL 3.0 CP module were used for the concurrent validity as suggested by the original developers of the CP QOL-Child. These questionnaires were translated into Thai and the reliabilities and validities were studied by Tantilipikorn et al^(15,16). PedsQL 4.0 Generic Core Scale measures HRQOL in four dimensions including physical function, emotional function, social function, and school function. There are 21 to 23 items for the child-self report and the caregiver proxy report. PedsQL 3.0 CP Module measures HRQOL specific to CP conditions. The Parent Report for Toddlers, aged 2 to 4, of the PedsQL 3.0 CP Module consists of 22

items with five dimensions including daily activities, movement and balance, pain and hurt, fatigue, and eating activities. The Child and Parent Report for Young Children, aged 5 to 7 and Children aged 8 to 12, of the PedsQL 3.0 CP Module consist of 35 items with seven dimensions by adding two more dimensions, school activities and speech and communication.

Procedure

Ethics approval was given by Mahidol University (MU-IRB 2012/018.0603). Prior to data collection, the informed consents were obtained by the parents and the children with CP who were willing to participate in the study. A researcher gave three questionnaires, the PedsQLTM 4.0 Generic core scale, the PedsQLTM 3.0 CP module, and the CP QOL-Child by counterbalanced order. If the children or the parents could not read, the researcher read for them and recorded their answers. If the parent and child with CP were in the same family, they were asked to refrain their discussion about the questionnaires till they completed all questionnaires. The parents and children with CP rested for 15 minutes or until they were ready to do the next questionnaire. If the parents or children were not ready to complete all the questionnaires at the same day, the researcher made an appointment to complete the remaining questionnaire as soon as possible

Data analysis

1. To examine the feasibility of the CP QOL-Child, the researcher calculated the percentage of missing value on each item of the CP QOL-Child. If the item's answers were missed at 50% or over, the item was considered to be cut off (Waters et al, 2007)⁽²⁰⁾.

2. To examine concurrent validity of the CP QOL-Child, the correlation between the CP QOL-Child and both the PedsQL generic core scales and the CP module were calculated by Pearson's correlation coefficients. The criteria for interpreting the strength of correlation⁽²²⁾ were 0.00 to 0.25 as little or no relationship, 0.25 to 0.50 as fair relationship, 0.50 to 0.75 as moderate to good relationship, and above 0.75 as good to excellent relationship.

Results

Demographics of children with CP and primary caregivers as participants

As demonstrated in Table 1, in children aged 9 to 12 years (mean \pm SD, 10 \pm 1), 60% were male and 40% of were female and the distribution of levels of gross

Table 1. Demographic characteristics of children with CP (n=65)

Children characteristics	Responded variables	Frequency; n (%)
Age (years); mean±SD	9 to 12	10±1
Sex	Male	39 (60)
	Female	26 (40)
GMFCS levels (n=65)	I	8 (12.3)
	II	9 (13.9)
	III	24 (36.9)
	IV	22 (33.8)
	V	2 (3.1)

GMFCS=Gross Motor Function Classification System; SD=standard deviation

motor function covered every level of GMFCS with level 1 at 12.3%, level 2 at 13.9%, level 3 at 36.9%, level 4 at 33.8% and level 5 at 3.1%. In Table 2, the caregivers, aged 23 to 63 years (40.6±7.7 years), were 90.6% female and 9.4% male. The children with CP having a caregiver were aged 4 to 12 years. The distribution of levels of gross motor function of the children covered every level of GMFCS with level 1 at 4.9%, level 2 at 12.4%, level 3 at 25.9%, level 4 at 49.4%, and level 5 at 7.4%. The caregivers' education levels were 43.75% primary or secondary school, 48.75% graduate, and 7.5% postgraduate.

Feasibility of CP QOL-Child Questionnaires (Thai version)

There were no missing responses in the CP QOL-Child (self-report). For the CP QOL-Child (primary caregiver), 28 items out of the 63 items had missing response but the missing answers were scattered.

Table 2. Demographic characteristics of primary caregivers (n=85)

Demographics	Responded variables	Frequency; n (valid %)
Age (years); mean±SD	23 to 63	40.6±7.7
Sex	Male	8 (9.4)
	Female	77 (90.6)
Age of children whom taken care of (years); mean±SD	4 to 12	7±2
GMFCS levels of the children whom taken care of (n=81)	I	4 (4.9)
	II	10 (12.4)
	III	21 (25.9)
	IV	40 (49.4)
	V	6 (7.4)
Education levels (n=80)	Primary or secondary school degree	35 (43.8)
	Graduate degree	39 (48.7)
	Post graduate degree	6 (7.5)

GMFCS=Gross Motor Function Classification System; SD=standard deviation

The missing responses were 1.2 to 7.1% and the total missing response was 0.84%. The three items that had missing responses at 7.1 percent were item#4--The way they get along with other children at preschool or school?, item#13--How they are accepted by other children at preschool or school?, and item#17--Their ability to participate at preschool or school? Item#4 and item #13 were in social wellbeing and acceptance domain, and item#17 was in participation and physical health domain.

Concurrent Validity of CP QOL-Child

The concurrent validity of CP QOL-Child was examined by correlating with PedsQL TM 4.0 Generic Core Scales and PedsQL TM 3.0 CP Module. Their correlations for two versions including self-report and parent proxy are shown in Table 3 and 4. According to the total scores of the questionnaires of both versions, the self-report and the parent proxy, the correlation coefficients between CP QOL-Child and PedsQL TM 4.0 Generic Core Scales were 0.23 to 0.25, meaning no or little correlations, at significance level of 0.05. Whereas the correlation coefficients between CP QOL-Child and PedsQL CP module were 0.38 to 0.49, meaning fair correlations, at significance level of 0.01. The correlations between CP QOL-Child and both PedQL modules by domain were varied. However, by domains, almost all correlations of CP QOL-Child and PedQL CP module were higher than these correlated with PedQL generic core scales.

Discussion

According to the characteristics of children with

Table 3. Correlation coefficients of CP QOL-Child with PedsQL TM 4.0 Generic Core Scales and PedsQL TM 3.0 Cerebral Palsy Module (Child self-report)

Domains of CP QOL-Child	PedsQL Generic	PedsQL Cerebral Palsy
Social well-being and acceptance	0.28*	0.37**
Functioning	0.24	0.37**
Participation and physical health	0.4**	0.46**
Emotion well-being	0.22	0.37**
Pain and impact of disability	-0.37**	-0.33**
Total	0.25*	0.38**

CP QOL-Child=Cerebral Palsy Quality of Life for Children; PedsQL=Pediatric Quality of Life Inventory

* Correlation coefficient is significant at the level of 0.05 (2-tailed)

** Correlation coefficient is significant at the level of 0.01 (2-tailed)

Table 4. Correlation coefficients between CP QOL-Child and PedsQL TM 4.0 Generic Core Scales and PedsQL TM 3.0 Cerebral Palsy Module (Primary caregiver report)

Domains of CP QOL-Child	PedsQL Generic	PedsQL Cerebral Palsy
Social well-being and acceptance	0.06	0.29**
Functioning	0.33**	0.53**
Participation and physical health	0.23**	0.45**
Emotion well-being	0.27**	0.40**
Access to services	0.28*	0.43**
Pain and impact of disability	-0.24*	-0.16
Family health	0.20	0.38**
Total	0.23*	0.49**

CP QOL-Child=Cerebral Palsy Quality of Life for Children; PedsQL=Pediatric Quality of Life Inventory

* Correlation coefficient is significant at the level of 0.05 (2-tailed)

** Correlation coefficient is significant at the level of 0.01 (2-tailed)

CP and the primary caregivers, the authors attempted to distribute across the required variables. The age group and gross motor severity levels were of concern. The distribution of the participants in the present study can be acceptable representatives.

Test-retest reliabilities and internal consistency of the CP QOL-Child were reported in acceptable levels⁽¹⁷⁾. The current study is the follow-up study to examine the validity of the CP QOL-Child (Thai version). The feasibility and concurrent validity were conducted.

Feasibility of the CP QOL-Child questionnaires (Thai version) for both self-report and primary caregiver proxy are acceptable. A few missing data, less than 10%, were found in some items. Therefore, this translated questionnaire is understandable for Thai children with CP and primary caregivers.

The validating of the CP QOL-Child was done with other QOL related questionnaire in both generic and condition specific types. On a basis of total scores of the questionnaires, the correlations are statistically significant ($p < 0.05$). However, most correlation in total scores and domain scores were fair. The main reason would be different measures of quality of life. The CP QOL-Child measure perspectives of quality of life specific to CP whereas the PedsQL in both generic and CP modules measure the frequencies of the problems and the difficulties that children experience. The validity of the current study is similar to Waters et al' study⁽²⁰⁾.

Conclusion

The feasibility of the CP QOL-Child (Thai version) was reportedly acceptable indicating clarity of the measure to the parents and children with CP. The concurrent validity showed low to fair correlations implying that the CP QOL-Child, focusing on perspectives of quality of life, may not measure the same constructs of the PedsQL Scales, which focused on physical difficulties. The CP QOL-Child (Thai version) would be the better choice to measure the core concepts of quality of life with acceptable reliabilities and validities.

What is already known on this topic?

The reliabilities of the CP QOL-Child (Thai version) were reportedly acceptable.

What this study adds?

The feasibility and validity of the CP QOL-Child (Thai version) were reportedly acceptable.

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Conflicts of interest

The authors declare no conflict of interest.

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